

## Conceptualizing the “Dis” of Our Abilities: A Heuristic Phenomenology

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**Abstract:** Social conceptions of disabilities rely on a positivist construction of a singular common normalcy which allows for the other-ing and subsequent devaluing of individuals who fall outside of that norm. Such devaluing and marginalization begins with and is evidenced in the very label *disability* and continues down a linguistically slippery slope of *deviance* and *abnormalities* until those being labeled as disabled can easily be conceived of as less than fully human. Nowhere, perhaps, is this phenomenon more poignantly played out than in schools, the very places that, ironically, purport to leave no child behind.

Guided by the voice of a character living with cerebral palsy and through the auspices of a heuristic phenomenology, I describe how my students and I, as individuals labeled with disabilities, experience, understand, and negotiate our differences within the confines of an education system rife with the pressures of standardization. In doing so, I shed light on the ways in which standardization dehumanizes individuals with differences, and I attempt to recapture my students' full humanity.

**Key Words:** curriculum, phenomenology, standardization

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“In the eyes of the world I’m a total retardate ... a *real* retard. Real in the same way that total means *total*. As in *total retard*.... They think it’s because my brain doesn’t work. They don’t know that is only partially true” (Trueman, 2000, 4-5).

Shawn McDaniels, quoted here, is the character stricken with cerebral palsy whose story constitutes Terry Trueman’s (2000) incisive book for young adults titled *Stuck in Neutral*. Like Shawn, I frequently battle misconceptions—telephone operators who believe the call has been disconnected, museum security to whom I appear to be disregarding explicit instructions, and that one ineludible student who on the first day of school asks (often with a mischievous glimmer in his or her eye), “So you can’t hear *anything*?” I can hardly blame any of them. Time spent in audiologists’ waiting rooms has familiarized me with the common conception of individuals with hearing loss. Having neither silver hair nor pervasively slurred speech, I simply do not fit the mould. Rather than believing I fail to live up to expectations, I prefer to conceive of myself as defying them. As my first audiologist commented shortly before informing me that testing had indicated a 35% binaural hearing loss, “I have no clue how you made it this far in school. In fact, I’m not sure how you even learned to read.”

Oddly enough, my interest in teaching students with disabilities arose long before I learned of my hearing loss, something which would have qualified me for special services. Now, the scenario reads something like a bad joke: what happens when you put a “deaf” teacher in a special ed. classroom? My humble response remains: amazing things.

Using Shawn's fictive yet candidly authentic voice as a guide, this paper explores how social conceptions of disabilities allow for the marginalization and dehumanizing of individuals who fall outside of the norm, and how my students and I, as individuals labeled with disabilities, experience, understand, and negotiate our differences within the confines of an education system rife with the pressures of standardization. In doing so, I explain how a paradigm shift from *curriculum as standardized criteria* to *curriculum as individual lived experience* allows my students and I to recapture our full humanity.

### Social (Mis)conceptions of (Dis)abilities

*"We are different!* I call my classmates retards because that's the word people use when they look at us. Retard means 'slow,' but it's also a word used for a whole class of human beings who are only slow because normal people try to make everybody do things in the same ways and at the same pace. We retards are retards only because normal people call us that" (Trueman, 2000, 42).

Linguistically speaking, the very terms *disability* and *disabled* necessitate positively construed opposites (Smith, 2006). These *able/disabled* and *ability/disability* polarities expose the ways in which notions of disability are socially constructed and rely upon a singular, positivist normalcy against which individuals are measured allowing for the other-ing and subsequent devaluing of those who negate the norm (Linton, 1998; Gallagher, 2006). Failing to subsist as an approximate match to society's conception of normalcy one is said to deviate from the norm. If one deviates from the norm then it is no linguistic leap to branding one a deviant, and inclusion among humanity and access to the full experience of being human starts to slip from one's grasp (Becker, 1963). It begins with the forced passivity of being disabled, in which one becomes the direct object rather than the agent of action, and continues through the discussion of one's abnormalities until one is inevitably placed away from the rest of society, on the margins of the human experience.

Nowhere, perhaps, is this phenomenon more poignantly played out than in schools, the very places intended to leave no child behind (Bejoian & Reid, 2005). In a standardized and norm-referenced era, it is no small wonder that many students already identified by schools as disabled, as falling outside of the norm, struggle not only academically but also personally with passing the test—after all, failing to do so carries stringent consequences in the various forms of remediation. Defined as the correction of a fault or deficiency, remediation enacted encompasses those means through which students' passive role is reinforced and marginalization is achieved as identified students are frequently removed from the general population, forced or coerced to participate in ways that limit personal choice, and further inhibited both academically and personally through banal, mechanistic curriculum. Subjected, limited, and mechanically trained, humanity slips away.

### What's in a Name (or a Label)?

"It probably sounds like I think I'm better than the other retards. Maybe I sound cruel to talk about us the way I do. Well, I absolutely don't think I'm better. I don't think there's some kind of retard ranking, with me on top and all the little stupids below me. I use the word 'retard' the way I use any word or words: dolphin, racehorse, sandwich, sidewalk,

and apple.... Words just stand for the things they are and for what people mean them to stand for” (Trueman, 2000, 41).

As an educator both living and teaching on the margins, I am simultaneously fiercely protective and highly demanding of “my kids.” A particular colleague of mine is especially gifted in bringing out this strange duality. While commenting on what he perceived as rigorous and equitable practice in my self-contained classroom, he continually referred to my kids as “’tards,” his pet name for identified students. Complimented and insulted simultaneously, I fired back that: yes, indeed, we all did rather well together—that is, for a bunch of ’tards at least. Recognizing the choice to include myself under the umbrella of his moniker, my colleague quickly replied that he had not been applying the term to me. My disability, he explained, did not count.

Just as it is faulty to assume that someone identified as having a reading disability will perform poorly in mathematics or that someone with poor vision is completely blind, assuming that all identified disabilities or differences are the same is absurd. Oswald and Coutinho (2007), in advocating for a perspective of individual differences within special education, refer to the currently recognized exceptionalities as “practical kinds,” categories which recognize fundamental differences between groups of similar disabilities (p. 7). This notion of practical kinds, of variation within the realm of disabilities, opens the door to those who, like my colleague, would rank our differences along continuums of visibility, severity, and impact.

For me, it raises many questions, chiefly: what does it mean to experience disability? As I reflect upon the daily lived experience of my classroom as well as of each individual who shares this space, I must admit that no amount of cupping their hands over their ears will allow my students to fully comprehend how my world sounds. Likewise, try as I might, I recognize my inability to understand in their totality the effects of Duchenne’s muscular dystrophy, the practically paralyzing fear of expressive language disabilities, or the anxiety of autism. Perhaps, I have often thought, the extreme variance precludes a common experiential thread (Linton, 1998; Oliver, 1998). Yet, although I cannot experience and comprehend, I am able to empathize. Hence, I am led to believe that, unique as we are, we share more than the space of my self-contained classroom to which my students were relegated in the context of these standardized times (Solis & Connor, 2006). What does it mean to experience disability in this curricular context? In search of an answer, I turn to the experts—my students and myself.

### A Sense of Place and Participants

“Although we’re located at Shoreline High School, we’re not really a part of it” (Trueman, 2000, 40).

My school is a part of a large, urban district known for its extreme poverty and transience. It is also, unsurprisingly, known for low passing rates on the state’s required exams for graduation. Narrowly conceived graduation requirements require all students to earn 40 credits (1 per semester in each course) and pass a battery of end-of-course assessments. Those unable to pass the tests must still earn the 40 credits, maintain a C average and 95% attendance rate, demonstrate effort through enrollment in additional remediation classes and summer school, prove commensurate competence through the auspices of a graduation portfolio, and continue to

repeatedly take the state-required tests which they have not yet passed. Those students unable to pass or to meet the laundry list of alternative criteria for graduation are counted by the state as drop-outs.

In response to state pressure to improve the district's overall test scores, the current superintendent instituted district-wide curricula and pacing guides as well as additional testing in the form of benchmarks which are administered at least three times a year. Although attaching high-stakes such as promotion to these assessments has been recommended, such mandates have not yet been made.

The school in which I teach houses approximately a thousand students in grades 5 through 12. Nearly 25% of those students enrolled have been identified as having a disability and needing special education services. As magnet programs have grown and faded throughout the district, the running joke amongst staff at my school is that we house the special ed. magnet. The school, which reopened in 2000 serving only grades 6 through 8, has been confronted with the many challenges of transitioning into a middle and high school combination. Amongst the many decisions to be made as a new grade level was necessarily added each year was how to handle self-contained classes at the high school level or whether a fully inclusive model should be utilized. Fears from both special education and general education staff over the difficulties they foresaw in including students with special needs as well as an underlying belief in the limited capacity of students in special education led the staff as a whole to choose to continue offering self-contained classes in nearly every core subject course throughout the middle and high school grades. Consequently, the rigor of modified special education curricula and the awarding of credit for self-contained classes have been topics of frequent debate.

As the school transitioned into a high school format, I too transitioned from an eighth grade inclusion teacher for all subjects to a high school self-contained English teacher. Because of my transition and the variety of high school grade levels I have taught, this is the third year I have spent in the classroom with many of my students who are now juniors. Due to the junior and senior English program I proposed several years ago, this also marks the second year I have spent with many of my seniors. To date, although several students' most recent scores came close, no one enrolled in my class has passed the required exam in English. Thus, my students will almost exclusively rely upon graduation waivers to obtain their diplomas, a fact of which they are well aware.

Thus, my class, which due to the constraints of construction has met in a temporary conference room in the school's media center for the last year and a half, has become a place where the work holds real-world value. Every piece of writing and every project in which we engage shares the common goal of proving each student's individual competency as a counter-narrative to their failure to meet the standards of testing. Initially dumbfounded and run ragged by the number of questions students posed about credits, GPAs, attendance rates and progress towards demonstrating standards-based criteria, I have since downloaded the many forms, instructions, rules, and regulations instituted by the state. Thus, conferencing with students about their portfolio work usually entails conferencing about their progress in meeting the additional criteria as well, and it is with a true sense of pride and accomplishment that most of my seniors close the cover of their portfolio one final time before submitting it to the school's principal. I would like to think that these accomplishments are impressive. However, "amazing"

is a term reserved for the daily witness I bear to the ways in which my students and I experience, understand, and negotiate our differences.

## Methods

From the group of juniors and seniors with whom I work, I selected six students to invite to participate in this phenomenological study. In choosing students, I attempted to represent variations in gender, race, and exceptionality in order to ensure that phenomena and experiences distilled from the data would stem from the experience of disability rather than other demographics. I then began the process of obtaining parent consent and student assent to participate.

## Procedure

Students participating in the study were asked to engage in individual interviews of which I made audio-recordings to ensure accuracy in quoting responses. The prepared interview protocol focused on: student response to the school setting, student knowledge of and response to personal disability, student perceptions of school relationships, and variations in student perceptions and response between home and school. Interviews were conducted in the privacy of my classroom outside of school hours, and I explicitly explained my desire to record the interview session to each student. Because of the rich history which I have shared with this particular group of students, I also reference my personal observations of classroom behaviors or occurrences.

In addition to student data, I include my own reflections upon the ways in which my disability pronounces its presence in daily life and specific memories of interactions in which my disability played an integral role (Patton, 2002).

## Data Analysis

In analyzing this collection of data, I referred to Moustakas' (1994) modification of the Stevick-Colazzi-Keen method of analysis for phenomenological data. Before conducting student interviews, I wrote my own responses to the interview protocol and made note of experiences in which I specifically remembered being confronted with or becoming keenly aware of my own disability.

Once my personal reflections were complete, I proceeded to interview students, taking care to transcribe each recording within several days of conducting the actual interview. I then sought to identify significant statements in each student transcript. Looking across all of the significant statements as well as my own reflection, I clustered similar comments or responses thereby creating themes which, from the data available to me, appear to constitute the essence of our experience as individuals with disabilities.

## Findings

### Normalcy Interrupted

“Everything that was ever going to be,

Everything that was going to become,  
Begins a slow unraveling” (Trueman, 2000, 31).

Kyra, a senior, responds, “I don’t,” when asked if she knows she is enrolled in special education, and then continues to explain, “I mean- I know, but if the teachers or nobody didn’t tell me, I wouldn’t know because - I mean- I feel that I learn like a regular student learns.” When asked how he knows he is enrolled in special education, George, another senior, responds with a hint of contempt, “Somebody told me,” and when asked if he knows why he was placed in special education, says rather quietly, “It wasn’t my fault.” “I didn’t know until I came here, and then they put me in smaller classes,” Dana, one of my juniors, recalls in responding to when she realized she was in special education. Molly, another junior, explains how she came to the realization that she had been diagnosed with a disability and placed in special education:

“Nobody ever explained it. In sixth grade they put me in for math and English and then in the seventh and eighth grade they had me in just for English.... Nobody explained it but I know why ... ‘cause I got dyslexia.... Yep. I have a learning disability.”

Essential to the experience of living with a disability is that moment in which your normalcy is interrupted by others who ultimately render you deviant, and in that moment, reality is rent in two. As evidence of your unique existence, your pre-existing reality continues for you to be normal, but now you must carry within you a second reality, in many ways as much your own but framed by another’s perspective. It is as though in being deprived of your abilities you gain a second pair of eyes with which you are forced to see yourself as the world perceives you. Although Du Bois (1903/1989) writes from his perspective as an African American, his notion of double consciousness also rings true for those living with disabilities: “It is a peculiar sensation, this double-consciousness, this sense of always looking at one’s self through the eyes of others, of measuring one’s soul by the tape of a world that looks on in amused contempt and pity” (p. 3).

### Jekyll and Hyde Duality

“Most of the rest of the strangers surrounded me and talked about me as though I weren’t there, and for them I actually wasn’t. The me they talked about ... is not the real me, not even the me my family knows” (Trueman, 2000, 28-29).

George, who has muscular dystrophy and uses a wheelchair, alludes to a kind of home/school duality when discussing how he believes people view him. “Some of them [people at school] probably have problems with me. Yeah because sometimes they say things. They just keep asking me questions.” Home, meanwhile, is a place where George describes himself as feeling “normal” and “awesome.”

I met Dana when she was in the sixth grade, and she tagged along with an older sister to the middle school volleyball practice. Every day, every practice she came. She interacted with the other girls. She participated in all the drills and scrimmages. She followed every order I gave the team. But Dana never said a word the entire season.

Two years later, after I had moved into the high school coaching position, the new middle school coach cut Dana from the team. I questioned her rationale. “She doesn’t talk.” Without

needing to look up, I knew the shadow in my doorway the next morning belonged to Dana's older sister. "Can't you do something?" I invited Dana to practice with the high school team. If she responded to my invitation, I did not hear her, but she showed up for practice every day, all season.

Another two years later, I am late for my fourth period class. Dana has stopped me in the library, and she talked my ear off:

"At school, I'm quiet. I don't talk. People at school see that I get good grades and do my work all the time. That's all they care. At home, sometimes I'm crazy silly. I talk all the time and drive my sister nuts. If I don't know people well, I just don't talk."

For Dana, who has an expressive language and speech disability, the boundaries between selves is as real as the school's walls inside of which who she is does not matter so long as she conforms to the image of the ideal student. Although I am reluctant to speak for Dana because so many others already have, I offer her story here:

"I think I am ready for some harder classes, some inclusion classes, but I didn't tell them that in my case conference. Everyone else was talking – about how I am doing and what classes to put me in. And they stopped and asked me what I thought, but I didn't say anything. They already knew what they wanted to do. I didn't want to argue, and I wasn't sure they would listen to me" (paraphrase based on Dana's interview).

For some students with disabilities like Dana, playing the part of the good student might get them by, but it might also fail to get them an education.

While Dana's experience speaks to the reluctance to advocate for themselves which students with disabilities sometimes experience, Kyra relates how her attempts to ask questions in class often turn sour: "I can ask them a question, and they get smart like 'Didn't I just say?' You know, I'm just asking a question. You know, you don't have to answer if you don't want to." Yet for Kyra, home is a place where learning naturally takes place. "I know about the government – politicians and all that ... because, my daddy, he's into all that stuff, so I just sit around and listen to him talk and stuff."

Whether the difference manifests itself in the incessant questions some students with disabilities face, the questions some never find the voice to ask or in the impatient responses to the questions they pose, students with disabilities appear to inhabit two worlds, a public one in which they must perform and a private one in which, in George's words, they get to be "normal."

#### Challenge(d)

"When people first meet me, they usually do their Annie-Sullivan-meeting-Helen-Keller-in-The-Miracle-Worker routine.... For some reason people always speak real slowly and real loudly when they're introduced to me" (Trueman, 2000, 55).

"Some people be like readin' baby books and like that's not cool," Molly responds when asked why she feels some of her classes are boring. Several minutes after listing U.S. history among her toughest classes, Dana lists it again among the classes she looks forward to attending.

“It’s hard, but it’s interesting,” she offers. “Easy classes are boring – like geometry. It wasn’t easy when Ms. Dames was teaching it, and I liked it... Mr. Harkberg just hands out worksheets with easy problems, and now I don’t like going at all.”

Like Molly and Dana, I too often react with greater resistance to the stinging insult of low expectations than I do to the burning rigor of a difficult task. As marked as the difference between *disabled* and *unable* or *disability* and *inability*, what it means to be “challenged” can be perceived in vastly different ways. For the able individual, being challenged is immediately understood as being presented with a difficult task. However, for the individual with disabilities, being challenged is frequently equated with the presence of that disability. Consequently, the opportunity to encounter and engage in difficult tasks, the chance to be challenged, is often withheld.

### No Difference When Everyone’s Different

“I hate the word ‘special’ when it’s applied to people. As in ‘he’s a very special person.’ Geez! Who isn’t!” (Trueman, 2000, 3)

When I ask if she believes she is different from other people, Molly’s eyebrow arches in a warning shot. Over the years, we have frequently engaged in playful verbal combat, and I have learned to watch the eyebrow, so I add in a mockingly serious voice, “Other than you’re cool and they’re not, of course.” She laughs, and then in a tone which clearly signals her opinion of the question as ridiculous, she sighs and lets out in a rush, “*Everybody* be different, Ms. B.” Yet, perhaps George said it best when he responded that he did not feel any different from other students at school and then added, “Everybody has problems with something.”

### Exceptional Empathy

In January, the grandparent of one of my students who uses a wheelchair and whose motor skills are rapidly deteriorating in the late stages muscular dystrophy gave me the greatest compliment of my teaching career: “No one has ever tried to see the world from George’s perspective before. Thank you for that.”

Perhaps having one’s own normalcy interrupted changes one’s perceptions and understanding of the intricate interactions of daily life. Perhaps in negotiating one’s own duality one learns to recognize and respect others’ attempts to do the same. Perhaps the innate and immediate knowledge that everyone is different fosters patience and tolerance. Though the explanation eludes me, the common thread of my students’ humanity does not. It manifests itself daily in the creative systems they derive for communicating things which I cannot fully hear. It fills the silent void when a classmate struggles through a difficult reading passage. Three years of unzipping pencil cases, opening books to the correct page, fetching paper, and making sure George’s hood is up during fire drills and cold bus rides home have served as constant examples. The ways in which it is acceptable to have bad days, their collective test anxiety, the act of lending a helping hand with the things they know a classmate finds difficult, and the shared joy of a senior’s success speak volumes about what my students know, wisdom I cannot take the credit for imparting.

### Conclusion



Left to their own devices, my students' curriculum is one of journeying towards better and more fully human versions of themselves, of *currere* (Pinar, 1994). There is a curriculum which without being standardized in no uncertain terms sets a standard (Hehir, 2005), not of language mechanics or vocabulary knowledge, but one of embracing humanity. From them we have much to learn. If we as educators continue to accept the narrowly defined and exclusionary standardized curricula of legislators, MBAs, and economists, we risk denying our differences, our individuality, and our opportunity for praxis. Eschewing a curriculum focused on producing and reproducing society's ideal norm requires us to stand naked in front of the proverbial mirror of perfection and admit the absurdity of standardization. It is only in shattering this socially constructed idea of normalcy that we can embark on a curricular journey which will honor our differences and experiences. Only then can we regain our humanity (Freire, 1970/2000; Pinar, 1994).

Until such a time, in the midst of this era of standardization which chooses to highlight our disabilities, my students' greatest ability goes unnoticed. Yet it is essential not only to the disabled experience but to the human experience, for what it has meant to collectively experience and negotiate our disabilities is to be deeply and honestly human in our foibles, flaws and follies, and to rise from the pieces of a normalcy the world has shattered only to approach that same world with eyes of empathy.

What happens when you put a "deaf" teacher in a special ed. classroom? In this case, I answer – amazing things.

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